NICE

Self inflicted harm—NICE in ethical self destruct mode?

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Some very bad old arguments need removing from NICE's latest report

Let me begin this editorial by reassuring readers that the journal does not hold any deep seated grudge against the National Institute for Health and Clinical Excellence (NICE). However, because the pronouncements of NICE are of great importance to the future of health care in England, and to a lesser extent in the other nations of the United Kingdom, and because NICE is often held up as a model for other countries to follow we feel that we have to comment when these pronouncements are less than ethically excellent. And in 2005 NICE just happened to have a particularly bad year with regard to the cogency of its ethical arguments, and this flow of bad argument extended right to the end of the year.

In December 2005 NICE published a report with the title *Social Value Judgments—Principles for the Development of NICE Guidance*, which considered whether social background, age, or lifestyle choices should ever influence NICE guidance concerning the health care provided by the National Health Service (NHS).[1] This report was endorsed by the NICE board and its guidelines are binding on all panels developing specific NICE guidance.

Here I want to focus on three areas of this report:

- The relevance of self inflicted conditions
- The relevance of socioeconomic status
- The relevance of stigma

I will not comment on NICE's methodology in coming to these conclusions, since that is the subject of a paper by John McMillan and colleagues, which is published in this issue of the journal.[2]

With regard to self inflicted conditions NICE has now bound itself to the following principle:

PRINCIPLE 10

Principle 10 states that:

> NICE and its advisory bodies should avoid denying care to patients with conditions that are, or may be, self inflicted (in part or in whole). If, however, self inflicted cause(s) of the condition influence the clinical or cost effectiveness of the use of an intervention, it may be appropriate to take this into account (NICE,[1] p 5).

In the press release trumpeting the report, Professor Sir Michael Rawlins, chairman of NICE, is quoted for the following wonderful *non sequitur* as the argument supporting principle 10:

> The report acknowledges that it can be difficult to determine whether illnesses are self inflicted or not. For example, there is no way of knowing whether or not a smoker who had a heart attack would have had the heart attack even if they had not smoked. As a result the report proposes that NICE should avoid discriminating against patients with conditions that are, or may be, self inflicted. However, if the self inflicted cause of the condition will influence the likely outcome of a particular treatment, then it may be appropriate to take this into account in some circumstances (National Institute for Health and Clinical Excellence press release: The real story behind NICE social value judgments guidance—final report published, NICE 2005/032, 8 December 2005:2).

So after very sensibly saying that it is difficult to establish whether a particular instance of an illness is self inflicted, Professor Sir Michael goes on to say that we can nevertheless rely on the self inflicted cause in decisions concerning the future. However, it is, of course, equally difficult to say whether a bad future outcome will be caused by the putative self inflicted cause. In the same way as we cannot say whether an individual heart attack was caused by smoking, we cannot say whether a future re-occlusion of the coronary arteries will be caused by smoking.

What would the consequences be of following NICE's principle? Let us consider a group of conditions where causation is much easier to establish in the specific case than in the case of ischaemic heart disease and smoking on which NICE seems to have based its guidance. Participating in a number of sports and leisure pursuits, even at amateur, leisure levels significantly increases your risk of sustaining significant ankle or knee ligament damage, requiring surgical reconstruction. This is, for instance true of alpine skiing, squash playing, soccer, and many other sports. Taking up these sports again after ligament reconstruction is obviously self inflicted, and does significantly increase the risk of a recurrence of the ligament problem. If NICE takes its own principle seriously we should therefore imminently expect guidance to NHS orthopaedic surgeons that they are only to reconstruct ligament injuries caused by participation in sports, if the patient promises never to engage in that sport again! This is probably not going to happen, but if guidance is eventually issued excluding unreformed smokers or obese people from treatment, but not unreformed fitness freaks, NICE will be guilty of iniquitous and unjustifiable discrimination.

There is also a deeper problem with the whole concept of self inflicted conditions, which is that there is no neutral lifestyle to use as the baseline for the assessment. All lifestyles increase the risk of certain conditions, and decrease the risk of others. There might conceivably be an optimal healthy lifestyle in the sense of a lifestyle producing the largest average number of healthy life years, but we do not know what that lifestyle is, and most of us have goals other than healthy life years that we pursue in our lives. It is simply deeply problematic to make NHS treatment dependent on lifestyle changes, because it imposes a specific set of societal values on individuals.

NICE also considers the relevance of socioeconomic status to priority setting and concludes with the following principle.

PRINCIPLE 8

Principle 8:

> In developing clinical guidance for the NHS, no priority should be given based on individuals' income, social class or position in life and individuals' social roles, at different ages, when considering cost effectiveness. Nevertheless, in developing its approach to public health guidance,

> NICE wishes its advisory bodies to promote preventative measures likely to reduce those health inequalities that are associated with socioeconomic status'' (NICE,[1] p 5).

On the face of it this principle seems fine. It essentially says that as far as treatment is concerned my social status should not matter and as far as public health is concerned it is legitimate to aim to reduce health inequalities even if these are linked to social status. On close inspection, however, the distinction between the clinical treatment context and the public health context is not innocuous.

The strong rejection of the relevance of social status in the clinical context will mean that those with high status will not be given priority by NICE in its guidance, and this is as it should be. But it will also mean that NICE has bound itself not to take into account whether its guidance concerning treatment will have differential effects for people of different social status. If NICE in the future has to choose between two treatments for a condition where one is slightly more cost effective than the other, but where the uptake of the most costly one will be distributed much more equally across socioeconomic groups, NICE cannot take this distributional effect into account. But if it is important ''to reduce those health inequalities that are associated with socioeconomic status'' it must take the distributional effect into account, whether the context is clinical treatment or public health.

What has happened is probably that NICE has forgotten what kind of body it is. It issues guidance that affects group of patients, it is not involved in clinical decision making for individual patients. And whereas the healthcare professional treating a patient should not take distributional effects into account, a guideline making body such as NICE must do so.

NICE recognises that some conditions are associated with stigma and that this may be a relevant reason for giving them special priority. It does, however, inexplicably come to the following conclusion in its principle 13.

PRINCIPLE 13

Principle 13:

> Priority for patients with conditions associated with social stigma should only be considered if the additional psychological burdens have not been adequately taken into account in the cost-utility analyses (NICE,[1] p 6).

But stigma is not only something creating psychological burdens in those being stigmatised. Stigma is a social condition that in most cases has social effects in terms of exclusion from certain social activities. Even a cursory examination of the literature on stigma, or a few seconds thought about some stigmatising conditions, makes the social nature of stigma obvious. Neither the stigma of being of the ''wrong'' race in a racist society nor the stigma of having HIV/AIDS is reducible to the psychological suffering of the stigmatised. So, even if the psychological burdens have been taken into account in the cost utility analyses, this does not exhaust the negative effects of most stigmatised conditions. If the condition leads to social exclusion, that is in itself a reason to prioritise it.

As I said at the beginning of this editorial, 2005 was a bad year for NICE on the ethical front, and this report on social value judgments definitely needs urgent revision. This revision should not wait for new developments in the literature on justice and resource allocation. What is needed is not the discovery of new arguments, but simply the removal of some very bad old ones. So let us hope that 2006 will be a better year for NICE.

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